

# An Urban Community-Based Cancer Prevention Screening and Health Education Intervention in Chicago

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## Synopsis.....

*Most types of cancer are disproportionately present in black populations. Among all ethnic and*

*racial groups, black people have the highest incidence of all types of cancer combined, experiencing the highest mortality and the worst survival rate. A major intervention effort has begun in Chicago, targeting women living in 10 south side community areas whose populations are almost all black and among the poorest in the city. The purposes of the intervention are to develop and evaluate ways to reduce morbidity and mortality from breast and cervical cancer.*

*Three outcome measures are being used, the proportion of women who receive Papanicolaou smears, breast examinations, and mammograms; the scores derived from a knowledge, attitudes, and practices survey; and the stage of diagnosed cancer. The results are being evaluated in three locations, the 10 target community areas, a Chicago Health Department clinic located in the community, and Fantus Clinic at Cook County Hospital.*

*The intervention consists of reducing barriers to care at both public clinic sites and delivering education and information within the community. Public health outreach workers who are culturally sensitive to the population bring word of the program to places frequented by women, including local businesses (such as beauty shops, grocery stores, pharmacies, and currency exchanges), public housing developments (one being the largest in the country), and facilities belonging to city services programs. The intervention was developed to permit its ready adoption in similar environments should the evaluation results prove its usefulness.*

**T**HE NATIONAL CANCER Institute (NCI) in 1984 announced a goal of reducing cancer mortality in the United States by 50 percent by the year 2000 (1). Since then, we have learned that one major obstacle in accomplishing the goal is the disproportionately high rates of cancer among black people. Among all ethnic or racial groups, black people have the highest incidence of all types of cancers combined, and experience the worst mortality and overall survival rates (2,3).

Data from NCI and the National Center for Health Statistics indicate that a major reason for the poor cancer experience of black people is late diagnosis, with blacks generally being diagnosed at a more advanced stage of the disease than whites.

Biological factors apparently explain only a small portion of blacks' excessive cancer incidence and mortality. Much of the difference is attributable to factors associated with low socioeconomic status, with blacks being disproportionately represented among the poor (4-6).

From the standpoint of cancer control, the major implications of low socioeconomic status include (a) inaccessibility and unavailability of health care; (b) low utilization and poor distribution and delivery of health services, including state-of-the-art cancer screening, detection, treatment, and rehabilitation services; (c) low awareness of cancer prevention concepts and behaviors; (d) and lack of acceptance of cancer as a real threat (5). High rates

of breast and cervical cancer reflect many of the leading issues in cancer control and help illustrate the dynamics of racial differentials.

As summarized in table 1, the annual age-adjusted incidence rate per 100,000 population for cervical cancer in the United States was 20.2 for black women and 8.8 for white women, during the years 1978-81. The age-adjusted mortality rates were 8.8 per 100,000 population for blacks and 3.2 for whites. The 5-year survival rates were 63 percent and 68 percent (7). Breast cancer was the most common cancer and the leading cause of cancer mortality in black women, with an annual incidence rate of 72 and an annual mortality rate of 26 per 100,000 population. Although black women have a lower breast cancer incidence rate than white women (whose incidence rate is 87), they have an equivalent mortality rate and a much worse 5-year survival rate (63 percent versus 75 percent) (7).

These statistics are related to less than adequate knowledge about cancer among blacks, their attitudes toward cancer and its detection and treatment, and health practices among blacks. Compared with whites, blacks generally underestimate the incidence of cancer and the ability to cure it or to prolong life after diagnosis. Furthermore, more blacks than whites indicate that they do not get adequate information about cancer (8). News about improvements in care and treatment and gains in survival rates after treatment may not be reaching the black community. Compliance with treatment is hampered by the problem of inadequate information (9).

A lack of information about cancer limits blacks' discussions about the disease. Blacks have been found to be less likely to talk about cancer with others, even close friends and relatives (8). The disease at times is referred to as "the big C," an indication of the significant fear with which cancer is viewed.

The experience of black men and women undergoing screening for cancer shows the magnitude of the problem of insufficient information about cancer contributing to the likelihood of less adequate detection and prevention methods. In the early 1980s, a survey conducted by Warnecke (10) compared the level of awareness between blacks and whites regarding specific procedures to detect cancer. Whites were found to be more likely to report that they had undergone a test for cancer. Some of the findings can be directly related to the amount of time and attention that health providers give to patient education. More blacks, particularly those

with low incomes, related that little or no time had been spent with them on explanations of procedures, so that fewer were able to say that a procedure had been performed and knew its purpose. More blacks than whites were unaware of breast self-examination (BSE) and Papanicolaou (Pap) smears as a means of detecting cancer.

According to a recent National Health Interview Survey supplement, twice as many black women as white women had never heard of a mammogram or a breast examination, although most women of both races had heard of a Pap smear (11).

The information collectively depicts a problematic reality. The objective situation for black people (reflected by adverse statistics on cancer incidence, mortality, and survival) and the subjective situation (the set of cancer knowledge, attitudes, and practices) influence each other. As long as black people keep dying from cancer at a disproportionate rate, they can be expected to be pessimistic about the disease. Many observers say that if we can change the beliefs of black people, the statistics will improve. However, in the authors' view, this is an interactional situation. As beliefs change, so will practices, and eventually, the mortality statistics (as long as appropriate resources are available). The salient statistics, whose implications are assimilated into the everyday lives of most people, play a large role in forming the attitudes and beliefs of members of the community. We believe that when progress is made in changing the statistics, we will be able to help change the beliefs.

## Intervention

In 1986, in response to the disproportionate burden of cancer in black people, the Special Populations Division of the National Cancer Institute (NCI) asked for proposals for reducing avoidable cancer mortality in black populations. Our proposal described a community-based health education and screening effort to explore ways to reduce mortality from breast and cervical cancer among black women who live in 10 poor areas on Chicago's south side, and who attend two large public clinics.

A review of the literature suggests that this effort may be one of the first to develop and implement such an intervention program for poor, black, urban women and to evaluate the effects. Our intervention is based on the assumption that the continuing cycle of excess cancer morbidity and mortality can be interrupted by working with trusted and integral community institutions to

Table 1. Incidence, mortality, and 5-year survival rates for breast and cervical cancer among black and white women, United States

Relative Category	Average annual age-adjusted rates per 100,000 population, 1978-81					
	Incidence		Mortality		5-year survival rates, 1973-81	
	Black	White	Black	White	Black	White
Cervical cancer .....	20.2	8.8	8.8	3.2	63	68
Breast cancer .....	...	...	...	...	63	75
Younger than 40 years .....	10.7	8.2	2.5	1.6	...	...
40 and older .....	179.3	221.1	68.1	70.2	...	...

SOURCE: Reference 7.

*'Our intervention is based on the assumption that the continuing cycle of excess cancer morbidity and mortality can be interrupted by working with trusted and integral community institutions to change inadequate beliefs which contribute to the cycle.'*

change inadequate beliefs which contribute to the cycle.

The project joins the resources of a major State academic institution, the University of Illinois at Chicago's School of Public Health and two major county and city institutions, Cook County Hospital and the Chicago Department of Health. In addition, community organizations, both public and private, within the target community areas support the work of the project. Funded for 5 years, the project was initiated in 1987. The intervention, which began in May 1989, is scheduled to end in 1991. The staff of more than 20 persons is made up primarily of nurses and other support staff, with physicians providing clinical direction and consulting services.

**Experimental design.** The project sites are 10 communities (city-defined geographic service areas) on Chicago's south side; Englewood Health Center of the Chicago Department of Health (CDH); and Fantus Clinic at Cook County Hospital (CCH), Chicago's only public hospital. Both the Englewood Health Center and CCH are publicly funded facilities which serve primarily medically indigent populations.

The 10 communities have a total population of about 368,000 (table 2). The residents are overwhelmingly black, have a significantly lower me-

dian income than the population of other areas of Chicago, and demonstrate many other characteristics associated with poverty. Foremost among the problems is a uniformly elevated cancer mortality rate.

We will evaluate the intervention for each of the three sites of the study (the 10 community areas, the CDH clinic, and Fantus clinic), using three outcome variables: They are scores on an index derived from a knowledge, attitudes, and practices survey; the proportion of women receiving screening tests (Pap smears, mammograms, and breast examinations administered by a health professional); and the distribution of the stages of diagnosed cases of breast and cervical cancer.

Data on a closely matched control group were collected at each intervention location just before the intervention was initiated (at baseline) and will be taken again upon completion of the study 18 months later. In addition to the outcome measures, we are collecting process measures to monitor our progress and to provide information which may suggest methods of improvement as the project continues.

The intervention involves multiple linked activities, including education and outreach in the community; education and recruitment in the clinic settings; breast and cervical cancer screening in the clinics; and diagnosis, treatment, and followup at Cook County Hospital. An intensive onsite training program prepared nurses to deliver the interventions according to the prescribed research protocols. Two public health nurses, assisted by two trained lay community outreach workers, are assigned to deliver the educational messages and specific information about the screening program to women living in the communities. Guided by a computerized data base of community contact points, the outreach workers systematically distribute the intervention materials and messages. Regular visits are made to each of the more than a thousand contact points.

Table 2. Demographic characteristics of the project's 10 Chicago communities, 1980

Area	Number	Population	Percent black	Percent female	Percent below poverty level	Median family income	Percent completed high school
Douglas .....	35	35,700	86.2	55	44	\$ 8,578	59
Oakland .....	36	16,748	98.9	54	66	5,554	41
Fuller Park .....	37	5,832	97.9	55	43	10,798	33
Grand Boulevard .....	38	53,741	98.8	54	56	6,945	35
Kenwood .....	39	21,974	77.0	54	26	16,139	69
Washington Park .....	40	31,935	98.8	55	49	8,157	40
Woodlawn .....	42	36,323	95.2	54	39	10,545	48
West Englewood .....	67	62,069	97.5	53	32	13,908	48
Englewood .....	68	59,075	98.2	55	40	10,597	42
Grand Crossing .....	69	45,218	98.3	55	26	14,085	54

**Rationale.** In the past, intervention approaches have been directed at critical public health problems. They included early sanitation measures to ensure safe milk supplies for infants, communicable disease control through massive childhood immunization programs, lead screening programs, and specialized infant mortality reduction initiatives. Recent preventive programs in maternal and child health serve as models for outreach into community environments to identify those considered at high risk and to recruit those most in need of health care services.

Low-income black women are disproportionately represented among those considered at significant risk for poor health and in need of programs for disease prevention and health promotion. They are less likely to have access to, and to avail themselves of, organized, formal health promotion and disease prevention programs that have been shown to have beneficial effects for reduction of disease. Such programs have had specific benefits among middle class white populations. Further, low-income black women are likely to have to rely upon public facilities for care and thus may experience more difficulty in followup of actual or suspected health problems, including cancer (12).

The health beliefs of a group contribute significantly to its members' participation in preventive health services. Studies of low-income groups at high risk for health problems have reported that they know little about the scope and availability of preventive health services. We seek to identify black women with increased need for preventive care, recruit them into care, and provide continuing preventive health services for them.

The intervention was intended to reach women through sustained interaction with a variety of community organizations and institutions in the target area. Intervention requires more than the

delivery of an accurate message. Rather, the project is guided by the hypothesis that true health education best takes place for women in the community if it is facilitated by other women and if it passes through convivial institutions that they accept (13).

**Contact points.** Contact points are agencies and institutions that serve women in the community who are eligible for intervention. The organizations include human service agencies, public and city institutions, public housing developments, health outreach facilities, businesses, schools, and religious institutions. All are important in reaching women from the communities. A community advisory committee, composed of community residents, business owners, professionals, and others, advises project staff members about community needs.

The outreach methods consist of several components directed toward increasing women's awareness of cancer, getting them to appropriately use the screening services offered, assisting them in following through on referrals for suspected malignancies in a timely manner, and reducing institutional barriers that inhibit them from receiving necessary care.

Outreach staff members distribute specially designed project flyers and posters, which are color-coded for each type of contact point. Staff members explain the purpose of the program to people managing the contact points in order to gain their cooperation in the effort. Where appropriate, they deliver presentations to community women, emphasizing the importance of early breast and cervical cancer detection through screening and breast self-examination. Women are encouraged to recognize their health responsibilities, as well as their ability to participate in promoting their own health. Referrals to the screening program are made at the end

*'We seek to identify black women with increased need for preventive care, recruit them into care, and provide continuing preventive health services for them, to serve as a basis for developing community outreach.'*

of each presentation. Posters and flyers bearing the photographs of four black women from the project present a brief message about early detection for breast and cervical cancer making an important difference and the availability of free screening services. Contact points being used in the intervention are

**Infant mortality reduction networks.** Infant mortality reduction networks (community network coordinating entities) include human services agencies that work in cooperation with health institutions to reduce black infant mortality in Chicago. The communities identified for the study are in areas designated for the infant mortality initiative in Chicago. Outreach workers for the initiative have been asked to distribute project materials as part of their efforts.

**Center for Inner City Studies (CICS).** CICS is a branch of Northeastern Illinois University. The center emphasizes concern for urban issues through educational programs for human services professionals; it is located in a community area. In addition to its academic component, the center offers seminars on a variety of topics, such as early childhood development and parenting, and cultural enrichment programs for people in the community. Project staff members are placing informational materials at CICS facilities to inform eligible women about project services and participation in CICS community forums and educational offerings.

**Businesses.** There are more than 300 businesses, including beauty shops, grocery stores, laundromats, clothing stores, currency exchanges, and pharmacies, in the outreach communities. Businesses were selected as contact points because women in the community use them frequently. Project staff members are distributing colored posters and fliers on a regular, scheduled basis. Presentations are made where appropriate. Similar out-

reach education provided in barbershops has succeeded in increasing awareness of men at risk for hypertension about blood pressure screening (14).

**City agencies.** Contact points have been established at facilities of city agencies, such as the Department of Human Services and the Department of Aging and Disability. Both departments provide a range of comprehensive services, including temporary emergency food assistance, referral services, special programs for youth, and services for older adults and people with handicaps. Project staff members place informational materials at the facilities, make presentations, and participate in other activities, such as health fairs.

**Chicago public libraries.** There are several full-service libraries in the communities that offer educational opportunities for women. Project staff members meet regularly with librarians to participate in the community education programs, provide informational materials, and make presentations.

**Religious institutions.** Project staff members are helping a city effort to improve delivery of health services through a partnership between religious institutions and the health department. Some institutions in the project communities have health outreach activities that receive support from the city, such as health education and public health nursing involvement. The more than 250 churches in the communities include storefront structures as well as those that are large and longstanding. The objective of working with churches is to inform members about the problem of cancer in their community and to offer women the project's screening services. Project staff members place informational materials regularly in community institutions and participate in health promotion programs, such as health fairs.

**Schools.** Project staff members are working with public school personnel to deliver interventions. Information is to be sent home with children twice a year to inform mothers and other women in the households about the project at the neighborhood CDH center. Presentations to parents, such as at Parent-Teachers meetings and community groups, are provided.

**Public housing facilities.** The communities have the largest concentration of public housing in the

city. More than 35,000 persons are listed as living there officially, but many more are estimated to live there. The developments are a mix of high- and low-rise structures and include the historic Ida B. Wells Homes and the more recent Robert Taylor Homes. Local advisory councils, representing tenants and the official management groups, are assisting in distributing information on the cancer project. Project public health staff place informational materials in the facilities at designated sites, such as management and council offices. Outreach staff participate regularly in programs offered in facility health promotion centers. These sites are operated by the Chicago Department of Health public health nursing staff. Presentations on breast and cervical cancer awareness by project staff members for community women are part of the intervention.

**Conclusion**

The project was designed to be adaptable to cancer control efforts in other places, and if it proves to be an effective strategy, could serve as a model for the delivery of community-based cancer control interventions. A comprehensive, multi-faceted approach is needed to alter the current experience of breast and cervical cancer in populations with high incidence of cancer. Linking community-based care that is accepted by women in the community with the major public hospital and providing outreach to inform and educate women can serve to reduce barriers that prevent timely care.

The project is an opportunity for investigators working cooperatively to conduct research with implications for more general use, as well as to provide a service to the black community. We expect that the effects of education provided community women will multiply as they tell others about cancer prevention and the project. If the intervention succeeds, it will not only bring women into our program, but it will strengthen community organizations and their links with residents.

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